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Engaging patients and family members in the evaluation of a mental health patient portal: protocol for a mixed methods study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-025508
Article Type:	Protocol
Date Submitted by the Author:	18-Jul-2018
Complete List of Authors:	Strudwick, Gillian; Centre for Addiction and Mental Health, Information Management Group Kuziemy, Craig; University of Ottawa Booth, Richard ; Western University Collins, Sarah Chyjek, Anna Sakal, Moshe Harris, Alexandra Strauss, John
Keywords:	patient portal, MENTAL HEALTH, patient engagement, family engagement, Health informatics < BIOTECHNOLOGY & BIOINFORMATICS

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Manuscripts

Title: Engaging patients and family members in the evaluation of a mental health patient portal: protocol for a mixed methods study

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Strengths and limitations of this study

- Patient and family member representatives have been engaged in the development of the study protocol, and will be involved in all aspects of data collection, analysis, and dissemination.
- This is the first known study to evaluate patient identified outcomes of patient portal use over a period of time within a mental health context.
- This study will be done using a specific patient portal technology at a single site, and thus the generalizability of the findings is unknown.

ABSTRACT

Introduction: Twenty percent of Canadians will experience a mental illness in any year. Mental health patient portals have been developed to support these individuals in taking more control over their own mental health and care. This may be done through electronic access to their health records and other supportive functions like completion of online self-assessments. To date, there has been limited research into the value that these portals may provide within mental health contexts. This study will identify what value mental health patient portals may offer to patients and their family members.

Methods and analysis:

This study will use a mixed methods design. Patients will complete a survey consisting of validated instruments at the time of enrollment in the portal, and at three and six months of portal use. Patient and family member focus groups will be conducted. Portal usage data will be collected to identify if there are differences in outcomes based on usage. The study will be done at Canada’s largest mental health and addiction teaching hospital, and will be conducted using a patient and family-oriented research approach, engaging these important representatives in all stages of the research process. The primary data analysis for the survey portion of the study will be done using linear mixed effect models, assessing the differences between patients with different portal usage levels. A thematic analysis will be conducted of the focus group transcripts.

Ethics and dissemination:

Approval from the study site’s Research Ethics Board has been obtained. The dissemination of findings of this study will be done through presentations at conferences, as well as a formal peer-reviewed journal article. Additionally, the research

team will work with a group of patients and family members to identify opportunities to complete knowledge translation and dissemination activities in non-traditional venues.

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INTRODUCTION

By the age of 40, half of Canadians have, or previously have had a mental illness³. It is therefore not surprising that mental illness is the leading cause of disability in Canada and the top priority of numerous organizations across the country^{1,4-6}. Despite the large number of individuals afflicted by mental illness, the Mental Health Commission of Canada has stated that "... using technology to control, detect, screen, or treat an illness is seemingly common. But not for mental health problems or mental illness. Technology in this area is not as widely used or invested in"⁷. Due to the limited use of technology in mental health organizations, there is also a lack of research into the value that these technologies may play in supporting mental health. The limited examination of this topic further contributes to mental health organizations not having the evidence to be able to justify the expenses associated with implementing such technologies, which has resulted in mental health organizations falling behind their counterparts with regards to technology adoption^{8, 9}.

One technology that could have benefits for people suffering from mental illness is a mental health patient portal (MHPP)². A MHPP is a secure online website that allows patients access to their mental health clinical information from a particular healthcare organization or system. Commonly, a MHPP is tethered to an electronic health record system where numerous health professionals have documented clinical notes. Information included in a MHPP may include: 1) lab results; 2) health professional clinical notes e.g. discharge instructions; 3) medication information; 4) results from other tests; and 5) a list of care team members. MHPPs may also have other functions such as being able to: 1) send a message to a health professional; 2)

request a prescription renewal; 3) book an appointment; 4) be reminded of an appointment; 5) update personal contact information; and 6) answer questionnaires to support health monitoring and care delivery.

At times, patients may want a family member to help them with their appointments or with accessing care¹¹. MHPPs often allow patients to give permission for a family member and/or caregiver to access their portal, enabling the family member to see some, or all of the patient's personal health information⁸.

As of 2018, there are nineteen known health organizations in the world that share mental health clinical notes with patients, and only two of these organizations are located in Canada^{2, 18}. Further, there is limited evidence to date to identify the value that these MHPPs may provide for patients and their family members. Findings from the few studies of portal implementations have suggested that MHPPs may support improved mental health recovery,¹² improved sense of empowerment,¹³ enhanced trust with health professionals, and better communication with health professionals.² However, sufficient evidence to support these potential benefits is lacking. Patient portals used in non-mental health contexts have shown value for patients in managing symptoms such as those related to taking medications,¹⁴; however, it has been argued that improvements in functioning could be a more meaningful outcome than addressing symptoms for people suffering from mental illness¹⁵. In addition, there is a growing body of literature highlighting the important role that families can play in supporting someone with mental illness^{16,17}. No known studies have been conducted to explore whether and how MHPPs offer families value in doing so. This study aims to address these current gaps in the literature.

METHODS AND ANALYSIS

Study Objectives:

The overall objective of this study is to determine what value MHPPs offer to patients and their family members. Primary, secondary and exploratory objectives are listed below.

Primary Objectives:

- 1. Determine if MHPPs are associated with improved mental health outcomes:
 - a. Identify if improved functioning is associated with the use of a MHPP.
 - b. Identify if mental health recovery is associated with the use of a MHPP.

Secondary Objective:

- 2. Identify if patient perceptions of empowerment, trust, and communication with health professionals change following the use of a MHPP.

Exploratory Objective:

- 3. Describe patient and family member perceptions of whether and how a MHPP offers them value.

Frameworks:

Two frameworks have been used to inform this study: 1) The Value-Based Health Care (VBHC) Delivery Framework has informed the conceptualization of this study²¹; and 2) The Strategy for Patient Oriented Research (SPOR) Patient Engagement Framework from the Canadian Institutes of Health Research has informed the methodological approach for this study. The central tenet of VBHC is that improving health outcomes must come from improving the value of care delivery¹³. Value, defined as outcomes over cost, becomes the overarching goal that unites all stakeholders

involved in care delivery for a patient's medical condition¹³. Outcomes include needs, wishes, and expectations of individual patients based on their unique contexts²². While the VBHC approach has been applied in primary care for patient medical conditions such as knee replacement surgery, it has not yet been operationalized for mental health care. Given the number of individuals impacted by mental illness, and the resource coordination and costs associated with the current delivery system, redesigning mental health care delivery using a VBHC approach could be of enormous benefit to society. In this study, the VBHC framework is complemented with the SPOR Patient Engagement Framework to: 1) inform the makeup of the current research team (including collaborators); 2) determine ways for a committee made up of patient and family representatives to meaningfully contribute to this study; and 3) engage a Peer Support Worker (a mental health worker with lived experience) in the various aspects of data collection.

Design and Approach:

The proposed study will use a sequential explanatory mixed methods design consisting of a series of surveys, MHPP usage data obtained from the software, and focus groups with patients and their family members. Patients enrolled in this study will complete a survey consisting of validated instruments at the following three time periods: 1) time of initial enrollment in the MHPP (baseline, T0); 2) three months of MHPP use (T1); and 3) six months of MHPP use (T2). These time periods were selected based on the literature that suggests that there may be an increased sense of 'hype' in the first couple of months when technologies are implemented and thus patients and their family members may have a different level of MHPP use during this

timeframe than they would otherwise²⁰. As well, it may take a number of months for there to be a noticeable change in the selected mental health outcomes measured in this study¹². Individual usage data of the MHPP will be collected on each participant from the portal software outlining the extent (frequency) and nature of their usage from the time they started using the portal until six months. Additionally, focus groups will be conducted with patients and family members who have used the MHPP for a minimum of three months. This study will take place over a 2-year time period. A summary of the design and approach is shown in Table 1. A Patient and Family Advisory Committee will be engaged during each stage of the research process (planning, execution, and dissemination) in order to ensure the relevance, meaningfulness, and feasibility of the study. This committee will consist of two patient representatives and two family member representatives.

Setting

This study will be conducted at Canada's largest mental health and addiction teaching hospital located in Toronto, Ontario. The study site employs physicians, nurses, occupational therapists, social workers, pharmacists, recreation therapists, personal support workers, behavioural therapists, peer support workers, and a variety of other health professional groups relevant to mental health clinical care. Patients served at the organization range from children to the elderly, and vary in terms of their mental health diagnosis (e.g. depression, schizophrenia, schizoaffective disorder, concurrent disorders etc.). Mental health services are offered through inpatient, outpatient, and partial hospital programs. The organization has the only standalone mental health emergency department in Canada.

The study site implemented a comprehensive electronic health record in 2013 with computerized provider order entry, clinical decision support, electronic medication administration with barcode technology, clinical documentation, electronic care planning, and laboratory results reporting and viewing. The organization obtained Stage 7 on the Healthcare Information Management Systems Society Electronic Health Record Adoption Model in 2017. In late 2017, the organization initiated efforts to introduce a patient portal tethered to the electronic health record, with a phased-in approach to the various portal functions such as access to documentation, self-assessments, and viewing test results.

Sample and Sample Size

Patient participants will be eligible to participate in the survey portion of this study if they: 1) have enrolled in the MHPP at the study site, and 2) have had access to the MHPP for less than 2 weeks. Patient participants will be eligible to participate in the focus groups if they completed surveys at both baseline/T0 and T1. Family member participants will be eligible if their family member is registered in a MHPP at the study site. All participants in the study will be over the age of 16.

Sample Size:

For the primary objective (objective 1a), a sample of 68 participants provides 80% power to detect a drop of 30% in the total World Health Organization Disability Assessment Scale (WHODAS) 2.0 12 items score from baseline/T0 to T2, using a small to medium effect size (Cohen's $d = 0.27$). This power calculation also assumes a paired comparison in a pre-test post-test design with a correlation between baseline/T0 and T2 WHODAS 2.0 score of 0.7, with a confidence level of 0.05, and two tailed tests. Based

on a previous MHPP study, a 30% drop-out rate is expected between T0 and T2, and therefore a minimum of 97 participants should be recruited to obtain 68 participants who complete all surveys at the various time points. To be conservative, this study will aim to obtain 100 participants. The change from baseline/T0 in percent and the power calculation was based on the data means and standard deviations for patients with mental health conditions³⁴ conducted with G*Power 3.1.9.2.³⁵ Likewise, a change of 8% in the MHRM scale can be detected with such sample size and 80% power, based on this data³⁶.

For the exploratory objective (objective 3), four focus groups will be conducted with approximately six to ten participants in each, totaling 24-40 participants. This number has been shown in past research to be an adequate sample size to obtain meaningful data for patient portal research.³⁷

Recruitment:

Participants will be recruited to participate in the survey portion of this study through the following three ways:

- 1) When participants are provided with a pamphlet describing how to enroll in the MHPP, a recruitment flyer will be attached to the back of this pamphlet.
- 2) As part of the registration process for the MHPP, patients will be emailed a registration link. At the bottom of the email with the registration link, recruitment information will be present.
- 3) When MHPP users sign on to their portal, the homepage will contain recruitment information for the study.

Once participants indicate they are interested in participating in the surveys, a registration link will be sent to them by a research assistant. This registration link contains a study information letter, consent information, and data fields to collect the minimum necessary personal identification information to conduct the surveys, such as email address, and name of patient as it would appear on their medical record.

At the end of the survey at T1, participants will be asked if they are interested, or their family member may be interested, in participating in a focus group. Participants enrolled through this approach will be provided with the logistical information so that they can decide which focus group to register for should they wish to do so. Recruitment methods for the survey portion of the study will also be used to recruit family members to the study.

Data Sources and Collection Procedures:

The primary and secondary study objectives (objectives 1a, 1b and 2) will be measured using a survey at three time points (baseline/T0, T1, T2) using validated instruments. The survey will be self-administered online through a secure survey website, or by a trained Peer Support Worker if participants would prefer the survey be administered over the phone. If a Peer Support Worker administers the survey, he or she will input the responses into the secure survey accordingly.

Participants will be emailed an electronic gift card by the research assistant each time they complete a survey to thank them for their time. Participants will have the opportunity to decide which gift card they would like to receive from a coffee shop, grocery store or movie theatre. The options for the gift cards were determined by patient

and family members who were consulted in the design of this study. If preferred by participants, physical gift cards will also be made available.

Demographic information (age, ethnicity, education, sex) will be collected during the baseline survey (T0). Other variables in the study will be measured using instruments, which are considered ‘gold standard’ in the field. Specifically, the primary and secondary objectives will be measured through a survey at all three-time points (Baseline/T0, T1 and T2). For primary objective 1a, *functioning* will be measured using the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) 12-item version²⁵. The reported Cronbach’s alpha for this measure ranges from 0.82 to 0.97²⁵. For primary objective 1b, *mental health recovery* will be measured using the Mental Health Recovery Measure (MHRM) 30-item version²⁶. The reported Cronbach’s alpha for this measure range from 0.86 to 0.94^{26, 27}. For the secondary objective (objective 2), *empowerment* will either be measured using the Consumer Evaluation of Mental Health Services (CEO-MHS)—Original Version^{28, 29} or a subscale of the MHRM. *Trust with health professionals* will be measured using the Health-Care Relationship Trust Scale (HCRTS) - Revised Version³⁰, and *communication with health professionals* will be measured using Health Care Communication Questionnaire (HCCQ)³¹. Acceptable Cronbach’s alphas have been reported from these measures in previous studies. In addition, the relationship between *functioning* and *mental health recovery* and individual patient portal usage will be evaluated. Permission has been obtained to use all instruments in this study.

Monthly usage data will be collected from the study site’s MHPP software for the duration of the study. Specifically, the number of times a patient participant has

accessed their record each month, and the functions that the patient uses, will be collected.

The exploratory objective (objective 3) will be measured through two 60-90 minute focus groups with patients, and two 60-90 minute focus groups with family members once they have used the portal for a number of months. Each focus group will consist of between six and ten participants, be audio recorded, and be facilitated by a trained Peer Support Worker using a semi-structured interview guide. All focus group participants will be provided with a cash honorarium as a thank you for participating in the focus group, and funds to cover public transportation costs.

Data Analysis

Survey:

Quantitative data analysis will be completed for the primary and secondary objectives (objectives 1a, 1b and 2), which were to identify how functioning, mental health recovery, empowerment, trust and communication with health professionals may change following the use of a MHPP. Analysis will begin with a description of the sample at T0 and at T2, and will be conducted for all metrics that are relevant to the study. A description of the demographics at T0 will also be conducted. A comparison between participants who dropped out and those who completed the surveys will be made using Fisher's Exact test for categorical variables, and the Mann-Whitney U-test for continuous variables. Participants will be classified into groups according to the frequency that they used the portal (low, medium and high) using the MHPP monthly usage data, with a focus on forming three groups of similar sizes. The comparison of these groups will provide additional evidence for how or if the use of a MHPP may

influence certain outcomes. The statistical analysis of the primary objectives 1a and 1b will be done using linear mixed effect models, where individual participants will be treated as random effects and the main effect of the portal will be estimated by the fixed effect of time. Time will enter the model as a categorical variable with three levels (Baseline/T0, T1 and T2), and a linear contrast will be used to test the change in the outcomes (WHODAS 2.0 and MHRM) from baseline/T0 to T2.

For the secondary objective (objective 2) the differences between baseline/T0 and T1, and between T1 and T2 will also be tested. All quantitative data analyses will be conducted using SAS v9.2 (SAS Institute, Cary, North Carolina, USA).

Focus Groups:

A qualitative data analysis will be completed for the exploratory objective (objective 3), which was to describe patient and family member perceptions of whether and how a MHPP offers them value. This will be done using thematic analysis drawing upon Braun and Clarke’s six steps: 1) familiarizing yourself with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report^{32,33}. All audio transcriptions from the focus groups will be transcribed verbatim and uploaded into NVivo 11 Pro (QSR International, Burlington, Massachusetts, USA) for data analysis. To enhance the trustworthiness of the analysis, a member of the research team and a research assistant will independently complete data analysis of the focus groups. They will then meet to compare their initial codes (including coding hierarchy); identifying similarities and differences among results and tracking these analytical findings in study memos. Inter-rater reliability will be calculated using Cohen’s kappa. If there is significant

disagreement regarding the themes, the two participants will jointly re-code sections of the transcripts, to resolve thematic differences.

ETHICS AND DISSEMINATION

This study has received ethical approval by the study site's Research Ethics Board. For the survey portion of this study, several decisions have been made to ensure that data collection is carried out in an ethical manner. When participants enroll in the survey portion of the study, they will have an opportunity to take as much time as they need to read an electronic study information letter, and ask questions of the research team before beginning the survey. The voluntary nature of the study will be communicated in this letter. Once participants have begun to fill in the survey, they can decide to stop at any point without penalty. Participant responses to the survey will be collected via an online survey platform. All data in the online survey is stored on a secure server at the study site which enhances the security of participant data.

With regards to the focus group portion of the study, informed consent will be obtained prior to the focus groups beginning. Participants will receive a copy of the study information letter and informed consent via email in advance of the focus group. Hard copies will also be available when they arrive for the focus group. Participants will have as much time as they need to read the document and ask any questions before the focus group begins. During the focus group, participants will be asked not to use any identifying information. If someone accidentally uses identifying information, it will not be transcribed from the audio. A pseudonym will be used instead in any transcriptions, and any reporting of the study results. Focus group transcriptions will also be kept in a secure research drive at the study site with access only being provided to the research

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team. Hard copies of consent forms from the focus groups will be kept in a locked filing cabinet in a locked room (study principal investigator’s office) at the study site.

A multi-pronged approach will be used to disseminate the findings of this study with relevant audiences. The committee of patient and family representatives will identify appropriate venues and types of materials for knowledge translation and dissemination activities. In addition, this group will advise the development of these materials so that they are relevant to the target audience.

Traditional dissemination strategies will also be used. The research team will share the findings of this study in an international field specific peer-reviewed journal, and will present the findings at relevant local, national and international conferences as appropriate. Additionally, to target mental healthcare administrators with technology decision-making responsibilities, an article may be written in a trade publication such as *Canadian Healthcare Technology*.

CONCLUSION

Once completed, this study will provide insights from patients and family members into the value that MHPPs may provide for these groups. The findings will specifically identify if use of a MHPP is associated with certain outcomes. As portal technology may be expensive and complex to implement within the mental health context, this study will provide some initial findings for organizations to consider when deciding whether they should implement and adopt MHPPs. By having patient and family member representatives in all stages of study operationalization, both the relevance and feasibility of the research will be enhanced. This research is a first step in understanding the potential outcomes of technology use within mental health settings.

Acknowledgements The authors would like to acknowledge Meera Pahwa, Madison Friesen, Kevin Leung, and Lauren Xie for their contributions to this study.

Contributors All authors were involved in the conceptualization of this the study. GS wrote an initial draft of the manuscript, and substantive feedback and revisions were completed by CK, RB, SC, JS, MS and AH.

Funding This study was funded by the Canadian Institutes of Health Research, Patient Oriented Research Collaboration Grant (Competition #201711), and the Centre for Addiction and Mental Health.

Competing Interests None declared.

Ethics approval Centre for Addiction and Mental Health Research Ethics Board

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Table 1. Overview of data source, variables and timeline

Data Source	Variables		
	T0 (Baseline)	T1 (3 Months)	T2 (6 months)
Survey	Functioning Mental Health Recovery Empowerment Trust with health professionals Communication with health professionals Demographic data	Functioning Mental Health Recovery Empowerment Trust with health professionals Communication with health professionals	Functioning Mental Health Recovery Empowerment Trust with health professionals Communication with health professionals
Focus Groups		Patient and family focus groups	
Usage Data	Number of accesses per month; functions of the patient portal accessed		

BMJ Open

Engaging patients and family members in the evaluation of a mental health patient portal: protocol for a mixed methods study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-025508.R1
Article Type:	Protocol
Date Submitted by the Author:	30-Jul-2018
Complete List of Authors:	Strudwick, Gillian; Centre for Addiction and Mental Health, Information Management Group Kuziemy, Craig; University of Ottawa, Telfer School of Management Booth, Richard ; Western University, Arthur Labatt Family School of Nursing Collins, Sarah; Columbia University, Biomedical Informatics and Nursing Chyjek, Anna; Centre for Addiction and Mental Health Sakal, Moshe; Hong Fook Mental Health Association Harris, Alexandra; Trillium Health Partners Strauss, John; Centre for Addiction and Mental Health
Primary Subject Heading:	Health informatics
Secondary Subject Heading:	Mental health
Keywords:	patient portal, MENTAL HEALTH, patient engagement, family engagement, Health informatics < BIOTECHNOLOGY & BIOINFORMATICS

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Title: Engaging patients and family members in the evaluation of a mental health patient portal: protocol for a mixed methods study

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Strengths and limitations of this study

- Patient and family member representatives have been engaged in the development of the study protocol, and will be involved in all aspects of data collection, analysis, and dissemination.
- This is the first known study to evaluate patient identified outcomes of patient portal use over a period of time within a mental health context.
- This study will be done using a specific patient portal technology at a single site, and thus the generalizability of the findings is unknown.

ABSTRACT

Introduction: Twenty percent of Canadians will experience a mental illness in any year. Mental health patient portals have been developed to support these individuals in taking more control over their own mental health and care. This may be done through electronic access to their health records and other supportive functions like completion of online self-assessments. To date, there has been limited research into the value that these portals may provide within mental health contexts. This study will identify what value mental health patient portals may offer to patients and their family members.

Methods and analysis:

This study will use a mixed methods design. Patients will complete a survey consisting of validated instruments at the time of enrollment in the portal, and at three and six months of portal use. Patient and family member focus groups will be conducted. Portal usage data will be collected to identify if there are differences in outcomes based on usage. The study will be done at Canada’s largest mental health and addiction teaching hospital, and will be conducted using a patient and family-oriented research approach, engaging these important representatives in all stages of the research process. The primary data analysis for the survey portion of the study will be done using linear mixed effect models, assessing the differences between patients with different portal usage levels. A thematic analysis will be conducted of the focus group transcripts.

Ethics and dissemination:

Approval from the study site’s Research Ethics Board has been obtained. The dissemination of findings of this study will be done through presentations at conferences, as well as a formal peer-reviewed journal article. Additionally, the research

team will work with a group of patients and family members to identify opportunities to complete knowledge translation and dissemination activities in non-traditional venues.

For peer review only

INTRODUCTION

By the age of 40, half of Canadians have, or previously have had a mental illness¹. It is therefore not surprising that mental illness is the leading cause of disability in Canada and the top priority of numerous organizations across the country². Despite the large number of individuals afflicted by mental illness, the Mental Health Commission of Canada has stated that "... using technology to control, detect, screen, or treat an illness is seemingly common. But not for mental health problems or mental illness. Technology in this area is not as widely used or invested in"³. Due to the limited use of technology in mental health organizations, there is also a lack of research into the value that these technologies may play in supporting mental health. The limited examination of this topic further contributes to mental health organizations not having the evidence to be able to justify the expenses associated with implementing such technologies, which has resulted in mental health organizations falling behind their counterparts with regards to technology adoption^{3,4}.

One technology that could have benefits for people suffering from mental illness is a mental health patient portal (MHPP)⁵⁻⁸. A MHPP is a secure online website that allows patients access to their mental health clinical information from a particular healthcare organization or system. Commonly, a MHPP is tethered to an electronic health record system where numerous health professionals have documented clinical notes. Information included in a MHPP may include: 1) lab results; 2) health professional clinical notes e.g. discharge instructions; 3) medication information; 4) results from other tests; and 5) a list of care team members. MHPPs may also have other functions such as being able to: 1) send a message to a health professional; 2)

request a prescription renewal; 3) book an appointment; 4) be reminded of an appointment; 5) update personal contact information; and 6) answer questionnaires to support health monitoring and care delivery^{9–11}.

At times, patients may want a family member to help them with their appointments or with accessing care¹⁰. MHPPs often allow patients to give permission for a family member and/or caregiver to access their portal, enabling the family member to see some, or all of the patient's personal health information.

As of 2018, there are nineteen known health organizations in the world that share mental health clinical notes with patients, and only two of these organizations are located in Canada^{12,13}. Further, there is limited evidence to date to identify the value that these MHPPs may provide for patients and their family members. Findings from the few studies of portal implementations have suggested that MHPPs may support improved mental health recovery⁶, improved sense of empowerment⁶, enhanced trust with health professionals, and better communication with health professionals.^{12,13} However, sufficient evidence to support these potential benefits is lacking. Patient portals used in non-mental health contexts have shown value for patients in managing symptoms such as those related to taking medications,¹⁴; however, it has been argued that improvements in functioning could be a more meaningful outcome than addressing symptoms for people suffering from mental illness¹⁵. In addition, there is a growing body of literature highlighting the important role that families can play in supporting someone with mental illness^{15,16}. No known studies have been conducted to explore whether and how MHPPs offer families value in doing so. This study aims to address these current gaps in the literature.

METHODS AND ANALYSIS

Study Objectives:

The overall objective of this study is to determine what value MHPPs offer to patients and their family members. Primary, secondary and exploratory objectives are listed below.

Primary Objectives:

- 1. Determine if MHPPs are associated with improved mental health outcomes:
 - a. Identify if improved functioning is associated with the use of a MHPP.
 - b. Identify if mental health recovery is associated with the use of a MHPP.

Secondary Objective:

- 2. Identify if patient perceptions of empowerment, trust, and communication with health professionals change following the use of a MHPP.

Exploratory Objective:

- 3. Describe patient and family member perceptions of whether and how a MHPP offers them value.

Frameworks:

Two frameworks have been used to inform this study: 1) The Value-Based Health Care (VBHC) Delivery Framework has informed the conceptualization of this study¹⁷; and 2) The Strategy for Patient Oriented Research (SPOR) Patient Engagement Framework from the Canadian Institutes of Health Research has informed the methodological approach for this study¹⁸. The central tenet of VBHC is that improving health outcomes must come from improving the value of care delivery¹⁷. Value, defined as outcomes over cost, becomes the overarching goal that unites all

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3 stakeholders involved in care delivery for a patient's medical condition¹³. Outcomes
4 include needs, wishes, and expectations of individual patients based on their unique
5 contexts¹⁹. While the VBHC approach has been applied in primary care for patient
6 medical conditions such as knee replacement surgery, it has not yet been
7 operationalized for mental health care. Given the number of individuals impacted by
8 mental illness, and the resource coordination and costs associated with the current
9 delivery system, redesigning mental health care delivery using a VBHC approach could
10 be of enormous benefit to society. In this study, the VBHC framework is complemented
11 with the SPOR Patient Engagement Framework to: 1) inform the makeup of the current
12 research team (including collaborators); 2) determine ways for a committee made up of
13 patient and family representatives to meaningfully contribute to this study; and 3)
14 engage a Peer Support Worker (a mental health worker with lived experience) in the
15 various aspects of data collection.
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33 **Design and Approach:**

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35 The proposed study will use a sequential explanatory mixed methods design
36 consisting of a series of surveys, MHPP usage data obtained from the software, and
37 focus groups with patients and their family members. Patients enrolled in this study will
38 complete a survey consisting of validated instruments at the following three time
39 periods: 1) time of initial enrollment in the MHPP (baseline, T0); 2) three months of
40 MHPP use (T1); and 3) six months of MHPP use (T2). These time periods were
41 selected based on the literature that suggests that there may be an increased sense of
42 'hype' in the first couple of months when technologies are implemented and thus
43 patients and their family members may have a different level of MHPP use during this
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timeframe than they would otherwise ²⁰. As well, it may take a number of months for there to be a noticeable change in the selected mental health outcomes measured in this study ⁶. Individual usage data of the MHPP will be collected on each participant from the portal software outlining the extent (frequency) and nature of their usage from the time they started using the portal until six months. Additionally, focus groups will be conducted with patients and family members who have used the MHPP for a minimum of three months. This study will take place over a 2-year time period. A summary of the design and approach is shown in Table 1. A Patient and Family Advisory Committee will be engaged during each stage of the research process (planning, execution, and dissemination) in order to ensure the relevance, meaningfulness, and feasibility of the study. This committee will consist of two patient representatives and two family member representatives.

Setting

This study will be conducted at Canada's largest mental health and addiction teaching hospital located in Toronto, Ontario ²¹. The study site employs physicians, nurses, occupational therapists, social workers, pharmacists, recreation therapists, personal support workers, behavioural therapists, peer support workers, and a variety of other health professional groups relevant to mental health clinical care. Patients served at the organization range from children to the elderly, and vary in terms of their mental health diagnosis (e.g. depression, schizophrenia, schizoaffective disorder, concurrent disorders etc.). Mental health services are offered through inpatient, outpatient, and partial hospital programs. The organization has the only standalone mental health emergency department in Canada.

The study site implemented a comprehensive electronic health record in 2013 with computerized provider order entry, clinical decision support, electronic medication administration with barcode technology, clinical documentation, electronic care planning, and laboratory results reporting and viewing²². The organization obtained Stage 7 on the Healthcare Information Management Systems Society Electronic Health Record Adoption Model in 2017²³. In late 2017, the organization initiated efforts to introduce a patient portal tethered to the electronic health record, with a phased-in approach to the various portal functions such as access to documentation, self-assessments, and viewing test results.

Sample and Sample Size

Patient participants will be eligible to participate in the survey portion of this study if they: 1) have enrolled in the MHPP at the study site, and 2) have had access to the MHPP for less than 2 weeks. Patient participants will be eligible to participate in the focus groups if they completed surveys at both baseline/T0 and T1. Family member participants will be eligible if their family member is registered in a MHPP at the study site. All participants in the study will be over the age of 16.

Sample Size:

For the primary objective (objective 1a), a sample of 68 participants provides 80% power to detect a drop of 30% in the total World Health Organization Disability Assessment Scale (WHODAS) 2.0²⁴ 12 items score from baseline/T0 to T2, using a small to medium effect size (Cohen's $d = 0.27$). This power calculation also assumes a paired comparison in a pre-test post-test design with a correlation between baseline/T0 and T2 WHODAS 2.0 score of 0.7, with a confidence level of 0.05, and two tailed tests.

Based on a previous MHPP study, a 30% drop-out rate is expected between T0 and T2, and therefore a minimum of 97 participants should be recruited to obtain 68 participants who complete all surveys at the various time points. To be conservative, this study will aim to obtain 100 participants. The change from baseline/T0 in percent and the power calculation was based on the data means and standard deviations for patients with mental health conditions²⁵ conducted with G*Power 3.1.9.2.²⁶ Likewise, a change of 8% in the MHRM scale can be detected with such sample size and 80% power, based on this data²⁷.

For the exploratory objective (objective 3), four focus groups will be conducted with approximately six to ten participants in each, totaling 24-40 participants. This number has been shown in past research to be an adequate sample size to obtain meaningful data for patient portal research²⁸.

Recruitment:

Participants will be recruited to participate in the survey portion of this study through the following three ways:

- 1) When participants are provided with a pamphlet describing how to enroll in the MHPP, a recruitment flyer will be attached to the back of this pamphlet.
- 2) As part of the registration process for the MHPP, patients will be emailed a registration link. At the bottom of the email with the registration link, recruitment information will be present.
- 3) When MHPP users sign on to their portal, the homepage will contain recruitment information for the study.

Once participants indicate they are interested in participating in the surveys, a registration link will be sent to them by a research assistant. This registration link contains a study information letter, consent information, and data fields to collect the minimum necessary personal identification information to conduct the surveys, such as email address, and name of patient as it would appear on their medical record.

At the end of the survey at T1, participants will be asked if they are interested, or their family member may be interested, in participating in a focus group. Participants enrolled through this approach will be provided with the logistical information so that they can decide which focus group to register for should they wish to do so. Recruitment methods for the survey portion of the study will also be used to recruit family members to the study.

Data Sources and Collection Procedures:

The primary and secondary study objectives (objectives 1a, 1b and 2) will be measured using a survey at three time points (baseline/T0, T1, T2) using validated instruments. The survey will be self-administered online through a secure survey website, or by a trained Peer Support Worker if participants would prefer the survey be administered over the phone. If a Peer Support Worker administers the survey, he or she will input the responses into the secure survey accordingly.

Participants will be emailed an electronic gift card by the research assistant each time they complete a survey to thank them for their time. Participants will have the opportunity to decide which gift card they would like to receive from a coffee shop, grocery store or movie theatre. The options for the gift cards were determined by patient

and family members who were consulted in the design of this study. If preferred by participants, physical gift cards will also be made available.

Demographic information (age, ethnicity, education, sex) will be collected during the baseline survey (T0). Other variables in the study will be measured using instruments, which are considered ‘gold standard’ in the field. Specifically, the primary and secondary objectives will be measured through a survey at all three-time points (Baseline/T0, T1 and T2). For primary objective 1a, *functioning* will be measured using the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) 12-item version²⁴. The reported Cronbach’s alpha for this measure ranges from 0.82 to 0.97²⁴. For primary objective 1b, *mental health recovery* will be measured using the Mental Health Recovery Measure (MHRM) 30-item version²⁹. The reported Cronbach’s alpha for this measure range from 0.86 to 0.94^{29,30}. For the secondary objective (objective 2), *empowerment* will either be measured using the Consumer Evaluation of Mental Health Services (CEO-MHS)—Original Version³¹ or a subscale of the MHRM. *Trust with health professionals* will be measured using the Health-Care Relationship Trust Scale (HCRTS) - Revised Version³², and *communication with health professionals* will be measured using Health Care Communication Questionnaire (HCCQ)³³. Acceptable Cronbach’s alphas have been reported from these measures in previous studies. In addition, the relationship between *functioning* and *mental health recovery* and individual patient portal usage will be evaluated. Permission has been obtained to use all instruments in this study.

Monthly usage data will be collected from the study site’s MHPP software for the duration of the study. Specifically, the number of times a patient participant has

accessed their record each month, and the functions that the patient uses, will be collected.

The exploratory objective (objective 3) will be measured through two 60-90 minute focus groups with patients, and two 60-90 minute focus groups with family members once they have used the portal for a number of months. Each focus group will consist of between six and ten participants, be audio recorded, and be facilitated by a trained Peer Support Worker using a semi-structured interview guide. All focus group participants will be provided with a cash honorarium as a thank you for participating in the focus group, and funds to cover public transportation costs.

Data Analysis

Survey:

Quantitative data analysis will be completed for the primary and secondary objectives (objectives 1a, 1b and 2), which were to identify how functioning, mental health recovery, empowerment, trust and communication with health professionals may change following the use of a MHPP. Analysis will begin with a description of the sample at T0 and at T2, and will be conducted for all metrics that are relevant to the study. A description of the demographics at T0 will also be conducted. A comparison between participants who dropped out and those who completed the surveys will be made using Fisher's Exact test for categorical variables, and the Mann-Whitney U-test for continuous variables. Participants will be classified into groups according to the frequency that they used the portal (low, medium and high) using the MHPP monthly usage data, with a focus on forming three groups of similar sizes. The comparison of these groups will provide additional evidence for how or if the use of a MHPP may

influence certain outcomes. The statistical analysis of the primary objectives 1a and 1b will be done using linear mixed effect models, where individual participants will be treated as random effects and the main effect of the portal will be estimated by the fixed effect of time. Time will enter the model as a categorical variable with three levels (Baseline/T0, T1 and T2), and a linear contrast will be used to test the change in the outcomes (WHODAS 2.0 and MHRM) from baseline/T0 to T2.

For the secondary objective (objective 2) the differences between baseline/T0 and T1, and between T1 and T2 will also be tested. All quantitative data analyses will be conducted using SAS v9.2 (SAS Institute, Cary, North Carolina, USA).

Focus Groups:

A qualitative data analysis will be completed for the exploratory objective (objective 3), which was to describe patient and family member perceptions of whether and how a MHPP offers them value. This will be done using thematic analysis drawing upon Braun and Clarke’s six steps: 1) familiarizing yourself with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report^{34–36}. All audio transcriptions from the focus groups will be transcribed verbatim and uploaded into NVivo 11 Pro (QSR International, Burlington, Massachusetts, USA) for data analysis. To enhance the trustworthiness of the analysis, a member of the research team and a research assistant will independently complete data analysis of the focus groups^{37,38}. They will then meet to compare their initial codes (including coding hierarchy); identifying similarities and differences among results and tracking these analytical findings in study memos. Inter-rater reliability will be calculated using Cohen’s kappa. If there is significant

disagreement regarding the themes, the two participants will jointly re-code sections of the transcripts, to resolve thematic differences.

Patient and Public Involvement

The conceptualization of this study, which includes both the determination of the research questions and methods described, were done in collaboration with a patient and family member representative prior to the submission for research funding. The study planning and execution involves a planning and family advisory committee with two patient and two family member representatives.

ETHICS AND DISSEMINATION

This study has received ethical approval by the study site's Research Ethics Board. For the survey portion of this study, several decisions have been made to ensure that data collection is carried out in an ethical manner. When participants enroll in the survey portion of the study, they will have an opportunity to take as much time as they need to read an electronic study information letter, and ask questions of the research team before beginning the survey. The voluntary nature of the study will be communicated in this letter. Once participants have begun to fill in the survey, they can decide to stop at any point without penalty. Participant responses to the survey will be collected via an online survey platform. All data in the online survey is stored on a secure server at the study site which enhances the security of participant data.

With regards to the focus group portion of the study, informed consent will be obtained prior to the focus groups beginning. Participants will receive a copy of the study information letter and informed consent via email in advance of the focus group. Hard copies will also be available when they arrive for the focus group. Participants will

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3 have as much time as they need to read the document and ask any questions before
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5 the focus group begins. During the focus group, participants will be asked not to use
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7 any identifying information. If someone accidentally uses identifying information, it will not
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9 be transcribed from the audio. A pseudonym will be used instead in any transcriptions,
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11 and any reporting of the study results. Focus group transcriptions will also be kept in a
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13 secure research drive at the study site with access only being provided to the research
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15 team. Hard copies of consent forms from the focus groups will be kept in a locked filing
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17 cabinet in a locked room (study principal investigator's office) at the study site.
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21 A multi-pronged approach will be used to disseminate the findings of this study
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23 with relevant audiences. The committee of patient and family representatives will
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25 identify appropriate venues and types of materials for knowledge translation and
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27 dissemination activities. In addition, this group will advise the development of these
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29 materials so that they are relevant to the target audience.
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33 Traditional dissemination strategies will also be used. The research team will
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35 share the findings of this study in an international field specific peer-reviewed journal,
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37 and will present the findings at relevant local, national and international conferences as
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39 appropriate. Additionally, to target mental healthcare administrators with technology
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41 decision-making responsibilities, an article may be written in a trade publication such as
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43 *Canadian Healthcare Technology*.
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47 **CONCLUSION**
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50 Once completed, this study will provide insights from patients and family
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52 members into the value that MHPPs may provide for these groups. The findings will
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54 specifically identify if use of a MHPP is associated with certain outcomes. As portal
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3 technology may be expensive and complex to implement within the mental health
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5 context, this study will provide some initial findings for organizations to consider when
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7 deciding whether they should implement and adopt MHPPs. By having patient and
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9 family member representatives in all stages of study operationalization, both the
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11 relevance and feasibility of the research will be enhanced. This research is a first step in
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13 understanding the potential outcomes of technology use within mental health settings.
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Acknowledgements The authors would like to acknowledge Meera Pahwa, Madison Friesen, Kevin Leung, and Lauren Xie for their contributions to this study. We thank the patient and family advisory committee for their contributions to this study.

Contributors All authors were involved in the conceptualization of this the study. GS and CK co-lead the writing of the original grant with substantive feedback from RB, SC, AC, JS, MS and AH. RB supported the development of the qualitative portion of this study. SC provided additional support in the organization of the original grant. AH and MS sat on the patient and family advisory committee. GS wrote an initial draft of the protocol, and substantive feedback and revisions were completed by CK, RB, SC, AC, JS, MS and AH.

Funding This study was funded by the Canadian Institutes of Health Research, Patient Oriented Research Collaboration Grant (Competition #201711), and the Centre for Addiction and Mental Health.

Competing Interests None declared.

Ethics approval Centre for Addiction and Mental Health Research Ethics Board

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Table 1. Overview of data source, variables and timeline

Data Source	Variables		
	T0 (Baseline)	T1 (3 Months)	T2 (6 months)
Survey	Functioning Mental Health Recovery Empowerment Trust with health professionals Communication with health professionals Demographic data	Functioning Mental Health Recovery Empowerment Trust with health professionals Communication with health professionals	Functioning Mental Health Recovery Empowerment Trust with health professionals Communication with health professionals
Focus Groups		Patient and family focus groups	
Usage Data	Number of accesses per month; functions of the patient portal accessed		